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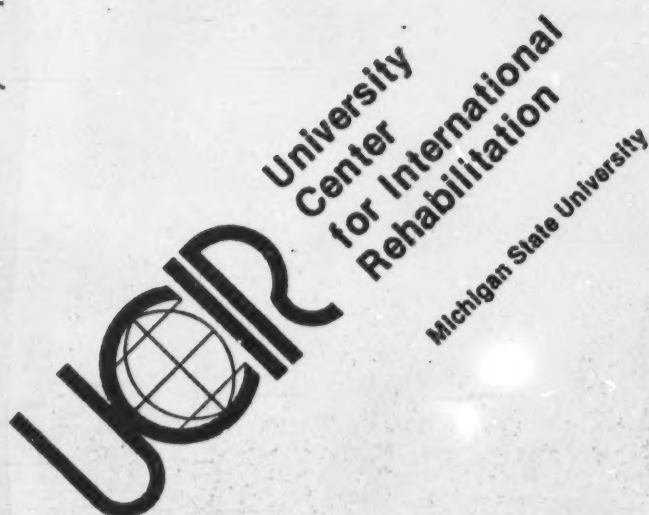
ABSTRACT

The author, a therapist, relates the 2 year process of psychotherapy with Heather, a 19 year old Down's syndrome girl. Psychotherapy was seen as the least restrictive alternative because it recognized that the girl, in addition to some concerns related to her handicap, was upset by her own inner emotional pressures and entitled to a neurotic depressive disturbance as a conflicted adolescent; and because the recommendation of insight psychotherapy was a normative alternative for an adolescent with neurotic conflicts and the capacities and motivation to work on them. The girl's record and test findings are reviewed, as are initial and subsequent meetings with her parents. It is explained that as Heather's relationship with her boyfriend Wayne (also retarded) developed, he also was included in the therapy sessions. Heather's progress is traced through living in her own apartment and her marriage to Wayne. Poems written by Heather are offered throughout the report. (SW)

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HEATHER'S STORY:
PSYCHOTHERAPY AND THE
PRACTICE OF THE LEAST
RESTRICTIVE ALTERNATIVE

January 1981

Gaston E. Blom, M.D.

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UCIR is located at Michigan State University and is funded by the National Institute of Handicapped Research, U.S. Department of Education, Washington, D.C. The center welcomes comments and inquiries.

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HEATHER'S STORY

Psychotherapy and the Practice of the Least Restrictive Alternative

On April 25th, 1976, Heather,* age 21, and Wayne,* age 25, were married in a small church ceremony. In attendance were Heather's mother and father, a friend from the tea room of the department store where Heather worked, Wayne's boss from the restaurant where he worked, and the family minister. Wayne's mother refused to attend since she was opposed to the marriage, and his father is divorced and has no contact with his son. I had received a mailed invitation but could not attend since I had moved to another city nine months previously.

You may immediately wonder why such an episode has any particular significance. Do not many young men and women get married at this age, sometimes against one or more parent's wishes? Is this then not a normal event? Of course the answer is yes. However, when one indicates that Heather has Down's syndrome and Wayne is retarded as a consequence of a birth injury, then a wedding is not viewed as a normal event.

As Heather's therapist and friend, I would have attended her wedding had I still lived in the city where it was held. In fact I was strongly tempted to fly 1500 miles to do so. I compromised by talking with Heather and Wayne on the phone and sending an electric popcorn maker as a gift from my wife and me. Later I also received a wedding picture. It would, of course, be normal for a friend to have such feelings and experiences. But is it normal or, in more correct parlance, professionally appropriate for a therapist to do so? At this writing there is no conflict in my affirmative answer to that question.

* The author has used pseudonyms for all names in this paper.

But the question of therapeutic style is perhaps secondary to the question of whether psychotherapy with a mentally retarded client is an appropriate undertaking at all. I initially found it difficult to fully accept that a retarded adolescent girl with Down's syndrome could participate in and benefit from exploratory insight therapy on a long-term outpatient basis. Professional training and the literature of psychodynamic psychotherapy had emphasized that insight is related to at least average cognitive capacities. Most of my clinical experiences had reinforced that assumption and had provided limited contact with mentally retarded children and adolescents.

Most textbooks present a limited and stereotyped view of Down's syndrome. One typical, current text states that emotional disturbance in retarded persons is more a social phenomenon than an intrapsychic problem and that it may be more effective to consult or train teachers, foster parents, or institutional attendants than to try to undo in psychotherapy damage resulting from misdirected upbringing. However, the authors state that in recent years professionals working with retarded persons have begun to consider psychotherapy as a suitable endeavor. But they go on to say that limitations in retarded clients of impaired verbal ability, poor impulse control, and passivity in problem solving situations necessitate modifications in the treatment approach, somehow implying that these limitations are unique to mentally retarded persons.

Current law states that in providing services for handicapped children, we must choose the least restrictive alternative. That is, we must use the most appropriate, normative, and remedial approaches, and the goal of these services must be to achieve the rights and opportunities which are as close as possible to those of the mainstream of society.

In choosing the least restrictive alternative, we must question the preconceptions and stereotypes which affect our professional behavior. In this case one must ask: Are ego strength and insight correlated with measured intelligence? Does cognitive capacity determine all behaviors in a mentally retarded person? Does mental retardation necessarily narrow the range of remedial alternatives when a psychological disturbance is present?

I felt that my decision to undertake psychotherapy with Heather was the least restrictive alternative. It was least restrictive in two ways. First, it recognized that Heather, in addition to some concerns related to her handicap, was upset by her own inner emotional pressures and entitled to a neurotic depressive disturbance as a conflicted adolescent. Second, the recommendation of insight psychotherapy was a normative alternative for an adolescent with neurotic conflicts and the capacities and motivation to work on them.

For two years I shared Heather's inner feelings about herself and her past and current experiences with the world of school, work, buses, home, and church. I tried to be helpful in dealing with many realistic problems and issues. But these endeavors would not have been possible without the support and confidence of her parents. On many occasions her parents were accused by professionals of not accepting Heather's limitations. They were also frequently questioned about the suitability of psychotherapy for Heather.

Heather's mother had previously taken risks, some of which had not had favorable outcomes. Yet she had the courage to take calculated risks again if they might enhance Heather's growth and progress. Heather's father was more skeptical about various ideas and proposals, but his love for his

daughter was very real. Furthermore, he could allow himself to be convinced by the proof that is in the pudding, where other fathers might have opposed or stopped a therapeutic program.

Heather's story begins in June 1973, when a pediatrician friend phoned and asked if I would be willing to do a psychiatric evaluation of Heather who had Down's syndrome and was almost nineteen years old at that time. Her parents had a number of concerns: Was Heather psychotic? How disturbed was she? What were her adjustment possibilities for a future? What recommendations could be given to facilitate her adaptation to life? I wondered if I had anything to offer. A psychoanalytically trained child psychiatrist is not usually consulted about the adjustment problems of mentally retarded persons.

My friend told me that questions about psychosis and severe emotional disturbance had arisen suddenly the previous month at a school conference where the parents were told about the results of psychological testing done twelve months previously in 1972. Twelve months is a long time to delay in communicating findings of such an ominous nature, regardless of their reliability. I was angered by the delay and wondered about the validity of the psychological findings, since Heather was still participating in a work-study school program. Certainly the normalization principle was not being practiced in relation to such a delay.

Before I consulted with Heather and her parents, I was sent Heather's school record, which contained the 1972 psychological evaluation. The psychologist's report began by indicating that Heather was seen "to bring her records into conformity with state regulations and to determine eligibility for continuing participation in a work study program" sponsored by the schools

and the state division of rehabilitation. In this report, the examiner noted Heather's apprehensiveness about testing and spent time putting her at ease by encouraging her to discuss feelings, family relationships, and school adjustments. To him, this discussion revealed some evidence of psychotic ideation and expression, pathological fear patterns, depressive episodes, chronic insomnia, preoccupation with blood and violent death, and occasional hallucinatory episodes. The psychologist had the impression that Heather had been subjected to unrealistic pressures for scholastic achievement by her parents. In his view these pressures were an important reason for her very troubled emotional state.

Psychological test findings indicated that Heather had an intellectual quotient of 49 on the Stanford Binet Intelligence Test, but that she achieved an intellectual quotient of 72 on the Peabody Picture Vocabulary Test. On standardized academic achievement tests she had a reading grade level of 7.5 and an arithmetic grade level of 3.6. It was interpreted that her highly verbal home environment was responsible for her verbal skills but perhaps at the expense of good emotional development, and that her excellent word recognition ability was not manifest in practical applications in the classroom.

Heather was classified as "a trainable rather than an educable mental retardate" and continued participation in the work-study program was advised. It was also recommended that a conference be held with her parents and that they be encouraged to take her for psychiatric evaluation and possible psychotherapeutic treatment, a conference that was held one year later! It was considered very important that the parents discontinue all attempts at formal reading instruction at home and that they use devices to help her acquire better knowledge of basic number facts. It was further recommended that the

parents avoid any suggestion of criticism or "invidious comparisons" with siblings or other children.

I had a number of reactions at this point, beyond my anger at the twelve month delay. Testing "to bring her records into conformity with state regulations" smacked of a cold, dehumanized process as did the classification as "a trainable rather than an educable mental retardate." I wondered about the accuracy of the impression of pressures and sibling comparisons from Heather's parents. I was surprised that Heather was able to verbally communicate so many concerns and problems to the psychologist. I wondered why the positive findings from psychological testing were discredited as being responsible for difficulties and for interfering with practical, concrete adjustment skills. I also wondered what kind of psychiatric evaluation and possible psychotherapeutic treatment had been expected.

When I first met Heather's parents, they were frightened and confused by the disturbing interpretations and conclusions of the school psychologist, whom they stated had not clarified the actual nature of Heather's home life and current school adjustment. While her academic grades in special classes were C's and D's during the 1972 academic year, Heather received satisfactory ratings in six different work experiences. The parents had sufficient personality strength to question the psychological interpretations. Heather's mother knew her daughter was sad and troubled, but she had every basis to doubt that Heather was psychotic.

Previous experiences with professionals had given Heather's mother good reason to question their judgments and evaluations. Sometimes their views had been presented in a unilateral way, disregarding her own observations and impressions. In a developmental questionnaire, Heather's mother reported

such an early experience with her obstetrician. "I remember seeing Heather in the bassinet in the delivery room and remarking that she looked a little mongoloid; the doctor thought I was a rejecting mother for this comment."

Heather's mother did not experience this earliest professional relationship with her obstetrician as one where she could voice her concerns and feel understood. Fortunately quite early in Heather's life, she relied on her own judgment, intuition, and values based on a confidence that many other mothers might lack. She also found a pediatrician who had respect and empathy for her dilemmas.

During our initial contact I found out that Heather was living with her parents, who are professional people; three older sisters were away from home. These sisters had been helpful and understanding about her slow development, but Heather was aware of her difference from them. She had participated in church activities and scouts. The family shared country singing as an interest. Heather insisted on becoming a country singer. She went to a sacred dance group at church where adults had helped her. She played with younger children but did not have friends of her own age. She was still very fond of a housekeeper, Auntie Bell, who helped in her early care. Heather maintained contact with her until Auntie Bell died.

Heather was lonely and spent much time writing poems that dealt with feelings about death, loneliness, nature, a wish for peace, wanted love, and religion. They were emotionally sensitive and expressive writings. Heather was preoccupied with death from an early age. At dinner time prayers she always included a prayer that the killing in Vietnam would cease. She had trouble expressing anger. When angry, Heather usually cried and went to her room. Her mother had difficulty in expressing angry feelings too, and when

her father became irritable, his anger was translated into physical symptoms.

Heather had difficulty with mathematics; she learned computations by rote but then forgot how to do them the next day. She slept fairly well. Heather had a favorite old dog, Marko. At this point, I felt the judgment of Heather's mother that Heather seemed troubled and sad but not psychotic was probably correct.

At our first meeting her mother brought Heather and expected that she could get home on the bus by herself. It was such a natural expectation that I was a bit surprised. Heather had mild Down's features. She was quite attractive, friendly, trusting, and dressed nicely. She enjoyed talking and I listened.

She came to tears easily yet her mood varied. I found her warm and likeable. She responded to questions but was also spontaneous. She talked about her loneliness. Her imaginary friends were real to her. She said she wanted to go to Hawaii or Nashville to see her favorite actors on TV. She described how she would go to Nashville and become a singer. Her parents and others did not think she was capable of such a career but she disagreed. She imagined things when she was lonely and her imagination became real. She described voices and visual scenes on falling asleep. She talked openly about some upsetting sexual experiences and didn't know if she could trust boys. She blamed her mother for this, saying she hadn't warned her. She hated math but loved writing. She was afraid of her father and felt he expected too much in math and on report cards. She was teased at school but did not fight back. She acknowledged it was hard to not be able to learn like others and not be able to do many things. She wanted to help others - people who were sick and hurt. She liked cops because they protected people.

In the second interview Heather came with her father, again with the expectation that she could get home by bus. She brought a list of problems she had written down which she wished to discuss. She spoke about fears of blood, skeletons, sirens, and arguments that her mother and father had.

My impressions were that she was not psychotic but had some problems with testing reality under the pressures of need, difficult situations, loneliness, and anxiety. She had problems in dealing with anger. She lacked relationships with handicapped peers. She described visual images while going to sleep which were not hallucinations but hypnogogic phenomena. Their content and frequency were disturbing to her. I prepared her for some psychological tests and indicated that I would talk with her and her parents following that.

I had ordered the psychological tests to provide further information on the degree of irrational thinking, the educable/trainable school placement decision, Heather's strengths and weaknesses in academic functioning, and indications for therapy. However, the psychodiagnostic testing also provided me a time delay to reflect on my uncertainty about the benefits of therapy in these circumstances.

The psychologist who did the testing was impressed with Heather's general appearance and overall social functioning. Heather had some difficulty in explaining why she was being tested but knew it had something to do with helping her parents guide her future. Her difficulty probably was a reflection of my uncertainty that had been communicated to her. While Heather wanted to go to Nashville and be with her country and western heroes, she thought she would probably continue in the work-study program for some time. Heather described how badly she felt when an adult would say "but she's so small" or

"oh, it's you." Throughout the testing session she used a good deal of teenage jargon like "dig it" and "cool." She occasionally used terms and words inappropriately without understanding, as if pushing herself too far to function as normally and adequately as possible. She gave many spontaneous observations about her life and her recent talks with me.

On intellectual tests Heather achieved an intelligence quotient of 73 on the Peabody Picture Vocabulary Test; overall intellectual functioning was estimated in the 50 to 60 intelligence range. Her academic achievement test performances showed greatest difficulty in mathematics and a very good concrete phonetic approach to reading and spelling.

On personality testing her thinking processes showed intactness on the Rorschach test, although her productions were limited. On the more structured picture cards of the Test of Emotional Development, a test somewhat similar to the Thematic Apperception Test, she elaborated stories at length in a coherent and logical way.

The psychologist was impressed with how Heather presented herself. Her spontaneity suggested she was interested in communicating and relating to others and in being understood. She was concerned about intellectual, physical, and sexual adequacy. Intense loneliness and low self-esteem appeared to move her towards paranoid-like thinking, but discussion of her difficulties might result in their abatement. Heather expressed a strong desire to continue her therapy sessions.

The psychologist suggested that clearcut decisions about educational planning should await further discussion in psychotherapy. Therapy was strongly supported in view of her high verbal abilities and strong awareness and sensitivity to things that were happening inside of her. Indeed the pic-

ture and recommendations which emerged from psychological testing were quite different from the negative image of the previous testing in 1972. The emphasis now was on strengths rather than weaknesses. Furthermore, I obtained consensus on my opinions and reassurance about professional doubts.

Following the psychiatric and psychological evaluations I met with Heather and her parents as promised. I tried to answer the original questions as best I could. Heather was not psychotic even though there were hypnagogic behaviors and at times shaky reality and fantasy boundaries in thinking. Her disturbance was a neurotic one based on adolescent development conflicts as well as feelings about being handicapped. I advised them to keep ideas about future adjustment possibilities open and recommended weekly therapy sessions to extend over a period of many months. Their response to these communications was relief that Heather was not "crazy," pleasure about individual psychotherapy, and some anxious uncertainty about the future. I agreed to contact the school people to see if a balance could be created between work and study experiences and also to achieve a working alliance with them. I question the degree of my success in this latter endeavor.

Over the course of two years I met with Heather sixty-six times; eight of the sessions included Wayne as their relationship developed. I talked with her parents ten times. There were also meetings with school staff, the association for retarded citizens staff, and child advocates. On a number of occasions I saw Heather in places other than my office--searching together for music companies who would transcribe her tapes at a reasonable price, having lunch with her at the tea room where she worked, and visiting her at the hospital when she had a sterilization operation.

Beginning with the second meeting, Heather would regularly write a list

of problems in a book which became her therapy book. These were the problems she wanted to discuss as well as take-off points for associated concerns and problems. When Heather became too uncomfortable or if I became too pressing, she would say, "ok, well" and go back to the list.

The list in the second interview consisted of:

1. Watergate is on my mind
2. How to hold a conversation without being interrupted
3. Work at Goodwill
4. Drug addicts and police
5. Make new friends
6. Two uncles died
7. Newer generation
8. Fears

Discussion of these topics revealed her conservative, fundamentalist values - belief in the president who is the head of our country and can't be wrong, police as friends and protectors, and the newer generation destroying the image of God. While I was not always in agreement with her belief systems, it became clear that they served a security motive and that relativism made her uncomfortable and anxious. There was some indication over the two years we met that as her self-esteem improved and her anxieties about death and anger diminished, Heather seemed more flexible in her values and more accepting of wrong-doing in the thoughts and actions of herself and others. At her graduation ceremony from high school, a young man streaked through the audience. As she told me about it she laughed, saying, "He was as naked as a Jay Bird!"

Work at Goodwill Industries, as one of her work-study assignments, made

her uncomfortable because of all the "deformed" and "crippled" people. She was anxious, cried, felt sorry for them, but didn't want to see them. This led her to talk with feeling about her handicaps: her sadness, anger, blame of parents, envy of others including her sisters, and the guilt such feelings engendered.

Slowly she accepted my encouragement that she did not have to use big words; her own were very acceptable. Later with her parents, she became willing to accept that she could not understand some situations, "I'm not that smart, but..."

Heather wrote poems to express various feelings. One poem among many dealt with sadness and concern for others. It was entitled "The Moslems," and it is cited exactly as it was written.

The Moslems

I feel for them
The hungry, sick, and old
I sure hat to see them die
On stretcher covered up
Do they go to church
I do
They walk on knees
Pray out loud
Shakes me up
Hand touch, feel for
Soul

Another poem expressed humor and was sung with gales of laughter in my office.

Song that wrote for Popa

I want a girl just the one who married
Dear old Dad

I want a mug of beer, just the way
 That my Daddy ever had
 A good old fashioned blut
 With heart so true
 But I want a girl that pickled
 Just the way that married
 Dear old Dad

The development of her relationship to Wayne had its beginnings in good relationships with family members. It was also preceded by attempts to create relationships with other young handicapped people in the work-study program. Heather's parents came to see that they were not allowing Heather's relationships with other handicapped people but were accenting contacts with the non-handicapped. This they had been doing unwittingly and without recognition. Heather's mother and I began a "program" to develop relationships, and it indeed was artificial and contrived. There was a Saturday Club available for retarded citizens in the community. Heather was reluctant to attend but agreed to try it for a month. Phone calls were made for enrollment. As it turned out, most of the people were older and did things which had no appeal or interest to her. They had group discussions which Heather called "shooting the hooley."

Next, the mother tried to contact parents of others who were in the special education program, but she encountered anxious doubts and suspicious concerns from these parents as well as from the school staff. Finally, she organized expeditions where two young women, together with Heather and her mother, did some shopping and went to the movies. While this proceeded well, there was no reciprocation from the others. However, Heather began to make use of her own relationship capacities and the permission and acceptance from her parents to move towards handicapped friends. The somewhat awkward steps

by her mother and me at least facilitated that move.

Her relationship to Wayne developed a few months later and quickly became one of love. Heather shared their love notes and news about their secret daily meetings after work. The love relationship of Heather and Wayne was a convincing one, and to support its fulfillment in realistic ways came naturally.

It took many weeks before I met Wayne. One afternoon he came with Heather to a Friday afternoon meeting. She had arranged his visit without prior discussion with me. Wayne understandably felt awkward and uneasy and asked me in a demanding tone why Heather was seeing a psychiatrist. I explained that Heather was not crazy but had problems that were helped by talking. He then wanted to know when treatment would end.

It was not until some time later at further joint sessions that he could acknowledge jealousy about Heather's warm feelings for me and his wish to have her share with him exclusively. I recognized the legitimacy of his feelings and wishes, and Wayne was puzzled by my acceptance. He gradually saw me as a substitute parent for both of them. He began to share his concerns about his mother. It was hard for him to believe that advocates and legal assistance were available to help realize his wish to consummate his and Heather's relationship in marriage. Wayne was quite frightened by the power he attributed to his mother - her legal custody and her threats to classify him as incompetent through the court. He had his own anxieties about separation and independence too.

Wayne viewed Heather's parents somewhat as his own parents and at times spoke about moving in with them if he was thrown out of his own house. This concerned Heather's parents who questioned the advisability of this possible

action. As father put it, bluntly and realistically, "I was worried about having one dependent upon us, but having two is too much and going too far." In retrospect, while not always appreciated, his firmness and definiteness at many times were helpful in establishing the reality of what Heather and Wayne wanted.

What was known about Wayne came from what he shared spontaneously with others. His family physician indicated that he had had a traumatic birth which resulted in stunted growth and slow development. He was an only child from an unhappy marriage which resulted in divorce. Although his father is living, on his mother's advice he told people that his father was dead. It took some time before Wayne could tell me otherwise, alluding to his father's having been admitted to a mental hospital. Wayne's mother had fostered his dependency on her, opposed his relationship to Heather, and actively resisted all attempts by various people to discuss this relationship and her feelings.

After a session where Wayne, Heather, and I discussed his mother's feelings, he wrote me the following courageous note.

Dear Doctor -

My mother and I heated talk about Heather and I. If I marry Heather. My life she could not live it. Both she and I want to go through with it. You might get a letter through the mail. I love Heather - she end it all. We are getting married. 23 years old and she could live our lives. If this brings her hard feelings, my Mom and I, that's too bad but nothing change.

P.S. My mom also told me she not mind who I married. Work out our own troubles. I don't care if I lose my Mom. I know we will. How about if get married 30th March.

Many attempts were made by Heather's mother through phone and letter to contact Wayne's mother. Eventually a letter came from her which shut the door on further communication. Wayne's family physician was reluctant to become involved in counseling her and advocated delay. At this point, child

advocates were involved through the offices of the local association for retarded citizens. An experienced, likeable, and sensitive young couple met Heather and Wayne through my aegis to help them in their efforts to live independently and be married. This couple continued their efforts after I moved to another city in July 1975.

A letter from these two advocates indicated the difficulties they encountered, as well as some gains.

Our relationship began shortly after our first visit with them and you. Heather was very responsive, but Wayne was suspicious and never did respond well. Heather and Debbie talked at least two times a week by phone, and Debbie would visit the tea room for lunch. There were difficulties in arranging get-togethers with both, since Wayne would have to lie to his mother about where he was going. We did manage a country western concert, a dinner at our home, and dinner at Heather's home. Debbie's discussions with Heather centered around her plans for a wedding, problems at work, and girl talk in general. Wayne's discussions with Tom concerned his mother's threats if he should try for independence or marriage. A meeting was arranged with Wayne, Heather, Heather's parents, Tom, Debbie, and the attorney for the retarded citizens organization. The attorney assured Heather and Wayne that he would assist them and support their effort to be married.

Tom made efforts to locate apartments for Wayne and a community mental health clinic to help him. After all these possibilities were explored, Wayne could not leave his home and try for independence from his mother. We did meet Wayne's mother which was a real experience. She was very affirmative in her position to stop Wayne from any marriage situation. After all of this surfaced, Wayne withdrew from Tom at the time a definite move from home was planned. Wayne just wasn't ready. It was difficult for Heather to understand our failure. After the peak experience, Heather told Debbie she did not want her to visit the tea room anymore, and she had had enough of the association for retarded citizens. The association for retarded citizens also indicated that Wayne's mother wanted no further contact with the office.

Heather remained undaunted and determined. While Wayne could not make the move, he remained firm, consistent, and loving in his relationship to Heather. After a number of planned dates for their marriage were postponed, Heather took initiative on her own. She moved out of her parents' home into

a small basement apartment which her parents helped her find. They were somewhat uncomfortable about this move but responded supportively to Heather's insistence on being independent and attempting to force a decision from Wayne. On returning home after helping Heather move, the parents found a poem on their bed pillow.

Poem

Theres not sun shine in my heart
 when i wake up in my bed in the morn
 my sun shine is not there.
 he's not here by my side when i
 cry why! some things wrong
 he is not here to hold me in the dark
 Like the way my folks hold each other
 in bed and make love.
 Lord my sun shine does not pour
 he's alone. if my folks want to make us
 happy They should let me have my
 sun shine back and in the
 family. We didn't mean no harm
 i know harm has been done
 but were both sorry honest we.
 are we didn't mean no harm
 i just want to have my happyness

Heather and Wayne were married. He had visited her at the apartment a short time before their wedding but continued to live with his mother following the marriage. He visited Heather regularly and indicated to her and her parents that he planned to move out at a date which coincided with a ruling on child support from his father. But this never took place.

At least one more theme needs to be developed in Heather's story. While this story has been presented in a somewhat orderly sequence, it is an im-

posed order. Themes in therapy actually occur in jumbled pieces and parts mixed together.

The additional theme is sexuality. In the first meeting Heather spoke of two upsetting sexual experiences. At that time she blamed her mother for not protecting her. By so doing, Heather failed to recognize the dignity of risk that is part of normalization. Later she held herself responsible for these events and expressed tearful guilt about "what I did." After recalling the episodes, we discussed how she could benefit and learn from them; that she did not have to deny her sexuality; and that there was a need to understand how, when, and where sexuality could be expressed. She was interested in reading more information, although she seemed to know a good deal already. I loaned her a book which she shared with Wayne who was much less informed.

On one occasion I talked frankly with both of them about their love and their sexual desires for each other. They were embarrassed yet pleased and relieved by my forthrightness. They blushed in my presence. I brought up the importance of birth control before marriage as well as after and discussed the different ways this could be done. They indicated that they would not have intercourse before marriage, and while I acknowledged their intent, I also said that sexual feelings could be strong and urgent.

This led to a series of meetings with Heather alone and to other meetings with them both on matters of pregnancy, their strong chances of having a handicapped child, the realistic limits to their adaptive capacities, birth control possibilities, and the nature of sterilization. I spoke in language that was as clear and direct as I could make it.

When the chance of having a handicapped child was first introduced, Heather responded empathically, "Who would know more about a Down's baby than

me. I am one. I know what it is like." From there we went into wishes and realities, and while there was freedom to think and to feel, I indicated where I stood. To have a child would be difficult for their life together, which itself would require full efforts to manage for themselves. If they conceived their own child, the possibility of having a handicapped child was very great. Raising a handicapped child, no matter how much loved, would be an added burden for them. Their desire to have children raised questions about a child's rights to have as normal a life as possible.

I recommended that Heather and Wayne see a pediatric geneticist for further counsel. It is clear from his report that they had already decided what to do.

When I asked them why they came, Heather did most of the talking and said that they were in love and wanted to get married. She knew she had Down's syndrome and understood that her children might have it. Since she did not want her children to have the problems she had, she felt she should be sterilized. We discussed this and mentioned the roughly 50% risk that any child she bore would also have Down's syndrome. Wayne was concerned lest the projected surgery would be painful and unpleasant and offered to be sterilized himself. We discussed that. He brought up the fact that his mother was not in favor either of the match or of vasectomy. We discussed the fact that the risk was Heather's and that we did not know his risk for retarded children. I supported them in their desires, agreeing that they might have a problem with the added burden of a child. I referred Heather to Dr. E. and offered to see them again if they wished. I only heard from them again by a Christmas card from Heather (several months later).

A month or so later Heather was hospitalized for sterilization. Wayne was in constant attendance and a stalwart source of support. They were both surprised that I came to visit Heather. The sterilization procedure was complicated by the need to remove vaginal adhesions that caused Heather more discomfort than she had expected and more than I and others had prepared her for. She took the post hoc explanations with trust and wrote "a beautiful letter" to the gynecologist thanking him. It was hand carried to his office.

My move to another city in July 1975 precipitated termination of our therapeutic relationship. It was a difficult emotional situation for all of us to deal with. Heather's parents were sorry, appreciative, and wished me well. Wayne said, "but you can't go, you have to be at our wedding." At our last meeting Heather wrote a poem which she presented with a bouquet of daisies.

Dr. Blom

As the sun shines Brightly we will still Rember you always and we will
Rem emb er all the good times we had with you and always be rem emb ererd
in a tear ful way all th ou gh things have to part

All that Wayne and I want to thank-you Very muchly for all your help.
and mam a and Papa wanted to thank-you Too. Ali we c an do NOW is s mile
and go on Living our Lives together. friends f ind people to L isen too.
i g uess iam Just the one

Let me w rite you a poem.

When a mother hold yer young
to her --.

At the time of termination, Heather and Wayne had a strong relationship and their relationships to advocates had possibilites. We had discussed finances, their earnings, and how they would manage a household, perhaps with some need for parental financial support. But they both wanted to manage themselves. What Heather did not have in math skills, she made up for in frugality. She managed a checking account with some help from her father and paid her own bills, including those for therapy. Life was now the central theme in her mind, in contrast to the concerns about death when I first saw her. Wayne's abilities and Heather's abilities complemented each other so that their combined strengths made partial independence feasible and realistic.

This hopeful prediction was at first tenuously supported by their getting married, although Wayne was not able to move away from his mother even with the support of other people. I have maintained some contact with Heather and her parents, and during the holiday season of 1977 my wife and I received a greeting card from Heather, then age 22.

Dear Family & Friends

Christmas Greetings from Dusky & Heather
(Dusky is my Siamese cat) Wayne has not made the break from his mother i think it never ever will be. Im now living in my sisters basement apartment. I have my work, my folks and family and church and I'm getting along just fine. We both wish you A Merry Christmas

And Happy New Year

Heather and Dusky

One would have hoped for a more successful progress report. But the lives of people do not always have the degree of success and happiness wished for, a normal phenomenon. Heather took stock of what positives she had and of what hopes might not be realized.

In June 1980 I was attending a conference in the city where Heather lives and had the opportunity to see her for the first time in five years. For two hours we reminisced about past events and talked about her current activities.

She was still working in the same tea room and got around by bus as usual. She had moved back to her parent's home but was more separated and independent. She was paying for her board and accumulating savings together with other funds for the future.

Three years ago, Heather had decided that she would no longer tolerate having Wayne visit her periodically when he could slip out of his mother's home. Either Wayne had to commit himself to her and the marriage, or she

would divorce him. After communicating this to him, he was still unable to respond or change. Heather then set a limit of one month. When this resulted in no action, she proceeded with a divorce and had her name changed back to her family name, even though "it is a much longer name." In reviewing her feelings she had worked through her loss and disappointment. She was not bitter, though she had wished for something better.

Most of the time with Heather was spent in recalling her visit to Nashville the previous summer, 1979. This had been her first significant trip by herself alone. Her trip took her via Dallas, where she changed planes to Nashville. A friend of her mother's from the local university met her at the airport and took her to dinner the first night, but otherwise she was very much on her own. She had her own motel room and was signed up for many tours and concerts. She managed by herself very well and plans to visit Memphis to see Elvis Presley memorabilia sometime.

Heather's parents are now in their late 60's. They have talked together with her about future plans, such as living in an apartment alone or with some supervision from the retarded citizens group. They have been working on Heather's future financial security and have discussed wills. Since her parents made out a will, Heather did also, making her own contacts with a lawyer.

The conversation with Heather and her parents was warm and enjoyable. It was one of those few experiences of being together not for therapy but for friendship.

As is clear from this narration of Heather's story, my role was one of combined therapist-advocate-friend. This was a role in which I had little experience and little help from professional theory, practice, or literature. On occasion I did not feel that my profession was a reliable ally. I tried

to facilitate what felt right and to oppose what seemed wrong. In that process I received support, indifference, inconsistency, and, at times, opposition from various agencies and professionals. Many times I neither felt nor acted neutral and would indicate my disagreement. Occasionally I found it necessary to take an extreme position with someone in order to obtain a sensible compromise.

Human service professionals have enormous power and influence over those defined variously as handicapped, ill, clients, and patients. Such power is the result of many forces: the knowledge gap between the server and the served, the sanction society gives to the authority of the professional, the nature of professional training and role induction that fosters the concept of authority, and the limited alternatives that many professionals offer. Still, human service professionals have the illusion that recipients of their care are free to accept, reject, or modify their services and recommendations or are really free to search for alternative suggestions and opinions from others.

How much true, appropriate, mutual participation exists between the professional and the client or his/her representative in decision making that affects the life of the client? In my experience, this type of participation tends to be more unique than usual. It stands in contrast to the more usual provider of services who makes most decisions in the authority stance.

I found the alternative, democratic stance difficult, yet helpful and reasonable. It was possible to have feelings and yet be objective and to take actions when they seemed called for. I am not advocating free license to divest clinical professional thought. Rather, I do challenge its rigidity and the validity of its practices when they are reinforced by questionable

knowledge and already biased experiences in relation to mental retardation.

Heather advanced in a world that tended to question and even to oppose her rights to as normal a life as possible. In presenting this story, Heather, her family, and I hope to make the issues in the least restrictive alternative more vivid to those who experience handicaps and to those who are their helpers. As Heather stated it in one of her letters:

i and Wayne will be thinking about you when you Give my story and i personally thank-you for lisening to me and knowing my ups and downs. and helping us Both with our Problems and how to face the world. of Love Heather and Wayne